Final Report: Inventory of Programs in Maryland

Introduction

Infant mortality has consequences for individuals, families, and society. Infant mortality is defined as the number of deaths to infants less than 1 year of age and is considered a sentinel indicator of a healthy society. Accordingly, reducing infant mortality and disparities in infant mortality are metrics by which we assess our progress toward improving population health and health equity. Recent efforts in Maryland have contributed to declines in the infant mortality rate (deaths/1,000 live births) from 7 in 2008-2012 to 6.5 in 2013-2017. Rates for black women in the state declined from 12.4 in 2008-2012 to 10.9 in 2013-2017, which were below the national rates for black women in the United States.

Nevertheless, Maryland's infant mortality rates remain higher than national rates, racial and regional disparities persist, and recent trends suggest an increase in infant mortality rates in rural areas of the state.

In 2018, the Maryland General Assembly passed a bill requiring the Maryland Health Care Commission (MHCC), in consultation with key entities within the Maryland Department of Health (MDH) and other stakeholders, to conduct a study on mortality rates for African American infants and infants in rural areas (2018 Md. Laws, Chap.83). Specifically, this study was designed to enable the General Assembly to understand the scope of infant mortality in Maryland, including its magnitude, how it varies across regions and racial and ethnic groups, and the availability of existing programs that address infant mortality in the state. Additionally, a detailed literature review on risk factors and effective programs for infant mortality was conducted. In keeping with these aims, the MHCC commissioned the University of Maryland, School of Public Health (MDSPH), Department of Family Science to conduct a study that would address several of these study aims.

This report summarizes information on existing programs that address infant mortality or its risk factors in the state of Maryland. We conducted a multi-pronged study in order to inventory existing programs and extract available information on each program using publically available information (i.e., websites and online program documents), and to implement a targeted survey. The survey was designed to supplement the web searches to collect more detailed information on program effectiveness and constraints, such as best practices and challenges for sustaining effective programs.

¹Braveman PA, Kumanyika S, Fielding J, Laveist T, Borrell LN, Manderscheid R, Troutman A. Health disparities and health equity: the issue is justice. Am J Public Health. 2011 Dec;101 Suppl 1:S149-55.

²https://health.maryland.gov/vsa/Documents/Reports%20and%20Data/Infant%20Mortality/Infant_Mortality_Report_2_017_20180919.pdf

CHARGE: INVENTORY OF STATE PROGRAMS

The specific charge for this component of the study was to conduct a comprehensive inventory of Maryland's local and state programs focused on infant mortality in collaboration with state staff, the advisory work group and subgroups. For this purpose, we defined a program with a focus on infant mortality as one that addresses infant mortality, specific causes of infant mortality, or its risk factors. The strategies applied were designed to be inclusive of all identified state, local, and nonprofit organizations, rather than specific to a few programs, and to be updated iteratively.

METHODOLOGY

Inclusion criteria

Programs were included if they directly addressed infant mortality, its causes (e.g., low birthweight, sudden infant death syndrome), or its risk factors (e.g., teen pregnancy, birth spacing). We further refined the inclusion criteria to only include programs that had an explicit focus the periods that could affect pregnancy and infant health (i.e., preconception, prenatal, or postpartum period). For example, programs in Maryland have been developed to address substance abuse (a risk factor for infant mortality); however, only one program specifically identified pregnant women as a target population of their program and was included in the inventory list. This inclusion ensures that the mission of each program is consistent with the broader aims of the MHCC study.

Search strategy

A list of programs was generated using documents on state-funded programs available through MHCC and MDSPH staff. To supplement this list, targeted web searches using Google search engine were also conducted. The following search strategy was recommended by the University of Maryland Public Health Librarian: ["Subject Term" program Maryland site:.org] or ["Subject Term" intervention Maryland site:.org]. The subject terms included "infant mortality," "birth outcomes," "preterm birth," and "low birthweight." Sites also included .gov and .edu extensions. Programs were added iteratively if they were identified during review of data sources. A question was also included in the survey that queried respondents on any additional programs related to infant mortality or its risk factors in the state.

A contact sheet was developed based on documents and searches. This contact sheet includes the specified websites, links to program documents, and contact information. Contact information of a program director or related position was collected for administering the survey. Additional programs

that were identified in the survey were added and noted in the contact sheet, but were not contacted to complete the survey due to time constraints.

Data sources

Information on identified programs was obtained from two sources: 1) publicly-available information from websites and online program documents and 2) a detailed survey developed in Qualtrics (see Appendix E2). The survey component of this study received MDSPH Institutional Review Board (IRB) approval.

Data collection

Information was extracted from websites or the survey based on criteria specified within the Interagency Agreement between MHCC and MDSPH. This included information on the type of organization, names of programs, duration of the programs, types of services offered, demographics and geographic areas of individuals within the program, program costs, funding sources and sustainability of the program, program evaluations and, if available, effectiveness of short and long-term outcomes, and best practices and challenges related to sustainability. Specifically, the information included:

- Type of program (home visiting, peer support, etc.). A checkbox list of known types of programs will be entered with an open-ended option to list other program types.
- Types of services offered within the program that address infant mortality or its related risk factors.
- Provider types involved in the program. This may include programs that are using pregnancy navigators and community health workers for pregnant women.
- The frequency and duration of the program components (i.e., when and how often services were provided).
- Entity that runs and manages the program.
- The number of individuals served and the target population of the program. If available, additional details will be collected on the demographics of individuals served, how the program reaches individuals, and who the program may not be reaching.
- The geographic area served within the state.
- Program costs (total and per capita) if available.
- Funding source and sustainability of the program.

 If available, evaluation and effectiveness information and information on best practices, challenges, and approaches to enhance cost savings. Specifically, impact on African American infants, rural infants, and overall outcomes (e.g., mortality, birthweight, preterm birth).

Information was collected differently depending on the data source. For the publically-available information, undergraduate and graduate research assistants reviewed websites and key program documents. Information that fit each criterion were populated using a Google spreadsheet. Information that was not available for a specific criterion was marked as unavailable, unclear, or left blank. Additional notes were collected in cases where content may be relevant, but did not meet a specific criterion in the extraction table.

Each question of the survey corresponded with an item on the tracking sheet. To reach non-state or non-local health department programs, an email was sent to identified contacts with an invitation to participate in the study and a link to the survey. Programs that had not responded to the initial email were sent two additional reminders. After the third attempt, the program was no longer contacted, and this information was documented on the tracking sheet. State and local health department programs were sent the same email and link to the survey; however, many of the identified state programs were not contacted because they did not provide direct services, local health department programs would capture the results, or we could not solidify appropriate contact information in time for their participation. For local health departments, the emails were sent to local health officers and coordinated through a state government contact.

Analysis

Web extraction

Extracted information from publicly-available data sources were reviewed and summarized. The web extraction was used to examine 5 main questions:

- What programs exist that address infant mortality or its risk factors in the state?
- What types of services are available within these programs?
- To what extent do these services address or have the potential to address specific risk factors in the population?
- How are these programs distributed in Maryland?
- What additional innovative approaches are used to support programs and their clients' needs?

Programs were divided into state, county, and non-profit or other types of programs. Details from the web extraction were further categorized into the types of services covered, populations targeted, and geographic (county-level) distribution. The summary statistic was based on the percent of programs that mentioned a particular type of service or population (i.e., density of each type of service, population served). The denominator for types of services covered was 83 total programs. The denominator for populations targeted and geographic distribution was 72 total programs, which excludes the 11 programs that focus on data collection or review and recommendations rather than service delivery.

The types of services were also sorted by the extent to which programs addressed clinical, behavioral, and social risk factors (see Figure 1 in Appendix C). This was determined based on whether a service or combined set of services could address a particular risk factor. The level of coverage was divided based on their density (summary statistic) into High (30% of programs or greater), Moderate (10-29.9%), and Low (< 10% of programs) coverage. The geographic distribution of programs within counties was also contrasted with the number of live births, number of infant deaths, and infant mortality rate in each county. Finally, innovative approaches that encouraged greater outreach within the community and supplementary services that would support further sustainability or reach of the program were also noted.

Survey

Response rates for the survey were calculated for state programs, local health departments, and non-profit/other programs based on differences in how these different groups were contacted. The survey was distributed to 3 programs within the state health department, 24 county health departments, and 16 other programs. Quantitative and qualitative survey data were organized into broad categories based on 4 themes:

- Program characteristics (organization type, types of services, provider types, outreach efforts)
- Client demographics (population characteristics, perinatal subgroups served, race/ethnicity distribution, age distribution, education distribution, rural/urban distribution, counties where clients reside, other services that are needed but not provided by the program)
- Sources of funding, financial sustainability, and efforts to control costs
- Best practices and challenges for maintaining effective programs

Summary measures of quantitative data were based on the percentage of programs reporting each category or characteristic with the exception of client demographics. For client demographics, we asked each program to summarize the percent distribution of their programs across race/ethnicity, age, education, and rural/urban/suburban categories. We summarized this information using the average (mean) percent distribution reported for each category. Additionally, we asked programs to report on the number of clients served for each population of infants, pregnant women, non-pregnant mothers, fathers, and other. We calculated a sum of the total numbers in each subgroup divided by the total number served across all populations to get the percentage of clients served across all programs.

FINDINGS - WEB EXTRACTION

What programs exist that address infant mortality or its risk factors in the state?

Overall, we identified a total of 83 programs in the state. Twenty-seven programs (32.5%) were part of Maryland government initiatives (Table 1). Of these state programs, the majority (n=23) were part of the Maryland Department of Health, 2 programs through the Department of Human Services, 1 program through the Department of Education, and 1 program through the Division of Vital Records. Thirty-one county health department programs (37.3%) were identified. Some programs were unique to a specific county (e.g., Center 4 Clean Start) and some were found across several counties (e.g., Healthy Families; Family Planning). Additionally, 25 non-profit or other types of programs were identified (30.1%), some of which included grantees from the Maryland Community Health Resource Commission (https://health.maryland.gov/mchrc/Pages/home.aspx). Eleven programs (13.3%) were identified as providing data collection, review, oversight, or recommendations, but not direct services in the state. Examples of these programs include Pregnancy Risk Assessment Monitoring System (PRAMS), Fetal and Infant Mortality Review (FIMR), Maternal Mortality Review Committee (MMRC), Birth Defects Reporting and Information System, Maryland Patient Safety Center, Perinatal Systems Standards, Title V Block Grant, Maryland Institute for Emergency Medical Services System, Child Fatality Review, and Maryland Hospital Breastfeeding Policy Recommendations, and Vital Statistics data.

What types of services are available within these programs?

The most prevalent types of services mentioned on program websites were referral services (45.7%), health education services (44.4%), home visiting (42.0%) (Table 2). These services were specific to the type of program and needs of their clients. For example, home visiting may address child development screenings, substance abuse, provide some prenatal care, or address other factors in the home.

Similarly, programs that offer referral services may provide linkage to substance abuse programs or identify women with specific health conditions during pregnancy and refer them to high-risk care. In terms of direct health care services, a number of programs provided prenatal (individual or group) (16.0%) and reproductive health/family planning services (18.5%). Social support services were also mentioned more frequently and included peer/family support or counseling (19.8%) and pregnancy support and navigation, including doula services (16.0%). Data collection, review, or recommendations was a key service of 13.3% of programs identified. Less than 10% of programs explicitly mentioned safe sleep resources (4.9%), teen pregnancy prevention (7.4%), smoking cessation (4.9%), substance abuse (9.9%), mental health services (4.9%), housing (3.7%), breastfeeding support (8.6%), and nutrition support (7.4%).

To what extent do these services address or have the potential to address specific risk factors in the population?

Using the percentage of infant mortality programs that mention specific types of services, we mapped this information by whether or not the types of services could address specific risk factors for infant mortality and the extent to which they were mentioned/offered from the identified programs (Table 3). Clinical and behavioral risk factors are the most proximal determinants to address disparities in infant mortality. Clinical risk factors showed low to moderate coverage based on review of publicly-available information. Specifically, reproductive health services and family planning could prevent sexually transmitted infections, short birth spacing, and teen pregnancy (Moderate coverage). Other health factors and behaviors, such as diabetes, hypertension, nutrition, psychosocial risks (depression, anxiety), substance abuse, and smoking were less likely to be mentioned directly (Low coverage). However, referral services, care coordination, or home visiting services may be addressing these risk factors or have the opportunity to more explicitly address these factors.

Socioeconomic and access-related risk factors varied in terms of coverage. There was a high level of coverage for access to care if we combined programs offering prenatal care and reproductive health care services, which has the potential to address preconception and prenatal health. Additionally, home visiting services provide an opportunity to extend care into the postpartum period. A number of services are designed to increase education on parenting, infant care, and safe sleep practices (high coverage). Additionally, social support could be enhanced through services that offer peer networks, group prenatal care, family counseling and pregnancy navigation. These services had moderate to high coverage. Finally, there was limited mention of programs that address insurance access (unless through

referral or care coordination), neighborhood factors, resources and income to support improved preconception, prenatal, and infant care, and racism; the latter of which could be addressed through expanding on existing programs that use community health workers, doulas, pregnancy navigators, and enabling services, such as language interpreters.

How are these programs distributed in Maryland?

Of the programs that provide direct services to the Maryland population (72 programs), we found that the websites or documents mention that they only serve or serve a large majority of low-income individuals, including un- or underinsured individuals (40.8%) (Table 4). The identified programs are mainly targeting pregnant women (42.2%), infants/children (19.7%), or non-pregnant mothers (29.6%), the latter of which could include parents of teenagers. Fewer programs mentioned the father or family specifically (11.6%). About 12.7% of programs mention serving specifically racial/ethnic minorities or marginalized populations and about half of all programs were in rural communities (50.7%).

Specifically, when we examine the geographic distribution of programs, we find the highest number of programs in the more populated counties (Anne Arundel, Baltimore, Baltimore City, Howard, Montgomery, and Prince George's) with the highest number of births, but not necessarily the highest infant mortality rates (Figure 1, Table 5). The number of programs per county ranged from a minimum of 8 programs (Somerset, Cecil counties) to 24 programs (Baltimore City). About 15.5% of programs mentioned that their services are offered in all counties.

What additional innovative approaches are used to support programs and their clients' needs? Finally, the website review also identified innovative strategies that some programs have adopted, which may better support the services offered or address their client needs. In particular, outreach approaches included hosting community baby showers to provide educational resources or infant care items, hosting information sessions or community input sessions in schools, communities, churches, and barbershop/hair salons, partnering with other local organizations, utilizing community health workers in at-risk communities, providing training online and frequently, and having a male involvement coordinator for teen programs. We also identified supplemental or supporting practices that could better support clients' or provider needs and goals. These practices included offering training that is online and/or provides continuing education credit for providers (e.g., recognizing and responding to child maltreatment, breastfeeding support in hospitals, life skills training), providing hospitals with specific designations (e.g., Baby Friendly Hospital), use of a reproductive life plan for preconception

care, telehealth approaches (telephone/email consultations or hotlines), and peer support or group classes (e.g., group prenatal care, networking opportunities with peers). Most notably, many programs discussed other activities that provided additional non-health related services and resources. This included support of family needs (e.g., child care, transportation, GED support, meal planning), resources (e.g., cribs, doula, educational toys and books), or enabling services (e.g., language services, disability support). Several programs also discussed engaging in policy and advocacy related to their mission.

FINDINGS – SURVEY

Response and completion rates

A total of 25 programs responded out of a possible 43 programs or health departments contacted (overall response rate: 58.1%); however, this varied based on how the survey was distributed as described in the Methods section above. The survey was sent to 3 Maryland state government programs and all 3 programs provided responses (response rate: 100%). Out of 24 counties or county-equivalents, 9 county health departments responded (response rate: 38%). Eight out of the 9 county health departments that responded (89%) were from one of the 18 counties designated as rural (response rate for rural health departments: 44%; response rate for urban health departments: 17%). Of the 16 other programs contacted (including non-profits, community organizations, university programs, and health centers), 13 provided responses (response rate: 81%). Out of all programs responding, 88% completed all of the survey and 12% completed approximately three-quarters of the survey.

Program characteristics

The program respondents were mostly from health departments (40%) and other non-profit (36%) or community-based organizations (12%) (Table 6). The most frequently reported types of services include referral services (88.0%), safe sleep³ (88.0%), pregnancy support and navigation (76%), and reproductive health/family planning (69.6%). Smoking cessation remained fairly common (64%), whereas nutrition (56.0%), substance abuse (44.0%) and mental health (47.8%) services were less common. Home visiting services were fairly common as well (60.0%), but may have been higher with greater participation from local health departments. Few programs reported providing direct general or group prenatal care

³ Did not distinguish between safe sleep education versus resources (e.g., provision of cribs)

(32.0% each). Housing services (12.0%) were mentioned but were not a major focus of the programs surveyed (Table 7).

A high percentage of the programs reported using nurses (72.0%), followed by health educators (52%). Social workers (44.0%) and community health workers (40%) were also common. Fewer than 40% of programs reported using physicians, nurse practitioners, mental health providers/substance abuse counselors, health administrators, nurse midwives, physician's assistants, or other types of providers (Table 8).

Additionally, we surveyed programs on the types of outreach efforts they use to reach clients. The majority used self-referral/word-of-mouth (80.0%), referral from a medical professional (76.0%), and referral from a social service professional (72.0%). Referrals, in general, reflected a large percentage of how programs reach clients and a little over half of the programs reported direct marketing/advertising (56.0%) (Table 9).

Client demographics

The majority of programs reported that they would describe the population of their clients as low-income (90.9%), pregnant women (90.9%), or postpartum women (77.3%). Additionally, around 60% reported that their clients were women with substance abuse concerns (63.6%) or women with specific mental health conditions (59.1%). Additionally, about half of the programs reported that they serve women with specific medical conditions (45.5%) (e.g., lack prenatal care, diabetes/hypertension, violence-related medical issue) or were from a specific race/ethnicity group (45.5%) (e.g., African Americans, Latinos, People of Color, Immigrants, Refugees) (Table 10). We also inquired about the number of clients served across all programs. Of the total number of clients served by these programs, 35.1% served non-pregnant mothers, 26.2% served pregnant women, 11.0% served infants, 7.8% served fathers, and 20.0% served other groups (e.g., general population, home births, teenage pregnancy, children 5-18, women of reproductive age) (Table 11).

Programs were also queried on the demographic distribution of their client base. The majority served by the program were Non-Hispanic black or African American (35.5%), ages between 20-24 (23.4%) or 25-29 (23.0%), had a high school degree (46.6%) or less than a high school degree (31.9%), and from urban areas (47.2%) (Tables 12-15). We also inquired about what specific counties the clients they serve resided in. The programs reported that a majority of clients resided in Baltimore City (40.9%) and Prince Georges county (40.9%) followed by Anne Arundel county (22.7%), Frederick county (22.7%), and Baltimore county (18.2%) (Table 16). These findings reflect both the programs that responded as

well as the distribution of programs within the state. For example, there were no programs that reported residing in Cecil, Garrett, Kent, Somerset, Wicomico, and Worcester counties, because of limited numbers of programs or local health department participation in the survey in those areas.

Finally, the survey inquired about services needed by clients that are not fulfilled by their program. Many of the services mentioned are not specific to the perinatal period but reflect broader social needs. These include housing assistance, transportation, child care, nutritional services, and navigation support, and translation/interpretation. Additionally, mental health and substance abuse services were mentioned by multiple programs, including specifically on-site mental health services, and substance abuse screening and treatment. Respondents highlighted the need for parenting and coparenting classes, programs targeting fathers, child birth education classes, infant CPR, and life course training, as well as more funding for safe sleep awareness. Opportunities for peer support were also mentioned, in addition to services provided by CHWs, home visiting nurses, and lactation consultants. Some respondents highlighted medical needs, including low-cost medical assistance for those not eligible for Medicaid, dental services, and accessible prenatal care. In order to enhance existing programs, respondents suggested giveaways, as well as healthy and nutritious meals or snacks for program participants, and funds to support longer follow up with mothers and children. Respondents also highlighted the need for advisory board meetings, staff team building, and workforce development.

Sources of funding, financial sustainability, and efforts to control costs Local Health Departments

- All 9 of the 9 local/county health departments that responded to the survey reported state
 grants or contract as sustaining the services they provide. In addition, 7 reported federal
 grants/contracts, 4 reported local grants/contracts, 4 reported public (Medicare/Medicaid)
 reimbursement, 1 reported private insurance reimbursement, 1 reported United Way, and 1
 reported private-public partnership funds.
- Of the 9 local/county health departments that responded to the survey, 4 indicated concern regarding future financial sustainability of their programs, 3 indicated they were "maybe" concerned, and 3 indicated they were not concerned about future financial sustainability of their programs.
- A common concern regarding financial sustainability was flat levels of funding despite increasing costs of program implementation. Other challenges mentioned included competition between health departments for limited funding, poor reimbursement rates, dependence on grants,

- inadequate workforce/staffing, and inadequate pay. One rural health department indicated a challenge reaching and maintaining caseload expectations.
- Efforts for cost savings include collaborating with community partners and other organizations, integrating programs, sharing resources, and doing outreach for multiple programs at once. In addition, staffing modifications include staff sharing, merged job duties, and increased reliance on CHWs rather than nurses.

Private/Community Programs⁴

- Program budgets varied greatly in their size, with reported program budgets ranging from approximately \$10,000 to over \$3 million. Sources of funding also varied, with programs reporting federal grants/contracts, state grants/contracts, local grants/contracts, private foundation grants/contracts, philanthropic donations, public and private insurance reimbursement, and community members.
- 9 out of 13 organizations (69%) indicated concerns regarding the future financial sustainability of their programs, while 2 (15%) reported maybe and 2 (15%) reported no concern regarding financial sustainability.
- Programs cited competing priorities and changing interests of funders as challenges for sustainability. One program specified that funds decrease when infant mortality rates decrease, and another commented that interest in pregnancy-related services is low. Additionally, programs highlighted flat funding despite increased costs for program implementation. Multiple programs reported challenges specific to serving uninsured women.
- Approaches to cost savings reported include partnering with other organizations/agencies, minimizing costs of program implementation, and teaching clients self-management skills. While multiple programs highlighted the use of volunteers, one response indicated that this effort to reduce costs may reduce program effectiveness.

Best Practices and Challenges

⁴ Some organizations provided data on multiple programs, while other organizations described a single program. For the purpose of this section, the unit of analysis is an organization, regardless of how many different programs they included in their responses.

The most common best practices that emerged in the survey findings were the use of incentives, outreach, and partnerships. Incentives were effective when engaging and retaining participation in the programs, especially vulnerable populations facing critical issues such as substance abuse and income restrictions. In addition to incentives, several organizations reported the importance of community outreach, one referring to it as "creative outreach" to engage the community. Survey participants also reported the importance of partnerships to leverage existing community resources that can address the unmet needs of the clients, especially those faced with challenges that the organizations are not equipped to address.

Funding was the most reported challenge among survey participants. They reported the need for funding to deliver primary services, as well as the need for funding to deliver specialty services that have emerged as needs; including programs to promote safe sleep. Several organizations reported the need for more resources to serve specific vulnerable populations (i.e. undocumented, low income, substance abuse). Although funding was a major challenge, participant recruitment, program enrollment eligibility, and transportation were major issues. Some organizations had difficulty recruiting clients while others experienced challenges retaining clients and demonstrating to the community the importance of participating in the programs. Transportation was another major challenge primarily because of geographical reasons (rural vs urban).

Programs of all types reported innovative outreach, importance of partnerships, and challenges with sustainable funding. In addition, most programs emphasized their focus on addressing the social and health factors of the clients which aligns with the literature. One primary difference across the organizations was that the use and benefit of community health workers were only mentioned among the private/community organizations.

Summary of Maryland's Managed Care Organizations (MCOs)

While not captured in the program inventory directly, Medicaid is a key provider of maternal and child health services, particularly for low-income women and children. In 2016, 38% of all births in Maryland were covered by Medicaid, including 53% of births to non-Hispanic Black women, and 61% of births to Hispanic women.

In Maryland, most Medicaid enrollees participate in HealthChoice, Maryland's Medicaid managed care program. According to a 2018 evaluation, in 2016 HealthChoice served over 1.1 million

Maryland residents, over 84% of Maryland Medicaid and Maryland Child Health Program enrollees.⁵ Members are enrolled in 9 managed care organizations (MCOs), which provide a range of clinical and care coordination services relevant to maternal and infant care.

All HealthChoice MCOs are required to provide medically necessary pregnancy-related services including comprehensive prenatal, perinatal, and postpartum care. The coverage must at least follow ACOG guidelines for pregnant and postpartum women. MCOs are also required to provide prenatal risk assessment, enriched maternity services including counseling and education, and home visitation. While home visitation service must be consistent with standard practice, it is unclear to what degree the MCOs utilize evidence-based home visiting programs. Some transportation assistance may be provided by MCOs, although this varies by plan.

Pregnant and postpartum women are considered a special needs population, therefore MCOs are required to ensure access to prenatal and postpartum care in accordance with national guidelines, appropriate referrals, and outreach to bring women in to care. HealthChoice MCOs have varied approaches to outreach for pregnant and postpartum women, and the Maryland Department of Health operates a dedicated helpline for pregnant women, the Maternal and Child Health hotline. Women who contact the help line are referred to Medicaid-funded Administrative Care Coordination Units (ACCUs) within each local health department, and the ACCUs assist women in navigating the health care benefits through their MCO.

In addition to the services provided by HealthChoice MCOs, a pilot program is currently underway which provides local governments with matching federal funds to expand evidence-based home visiting programs (Nurse-Family Partnership and Healthy Families America) for at risk pregnant women and children up to age 2. Through this pilot, federal funds have been provided to serve a limited number of families in Harford and Garrett counties.

HealthChoice MCOs outperformed national averages for both timeliness of prenatal care and frequency of ongoing prenatal care. The HEDIS measure for timeliness of prenatal care assesses the percentage of deliveries for which the mother had a prenatal care visit in the first trimester (or within 42d of HealthChoice enrollment). In 2016, 87.6% of HealthChoice deliveries met this criterion, compared with 81.7% nationally among Medicaid HMOs. The HEDIS measure for frequency of prenatal care assesses the percentage of deliveries for which mothers received the expected number of prenatal visits, accounting for gestational age and time of enrollment. In 2016, 71% of HealthChoice deliveries

_

⁵ Evaluation of the HealthChoice Program CY 2012 to CY 2016. July 3, 2018. Accessed at https://mmcp.health.maryland.gov/healthchoice/pages/HealthChoice-Evaluation.aspx

were by women who had received >80% of expected prenatal care visits, higher than the national rate. However, recent evaluation of the HealthChoice's Value Based Purchasing (VBP) initiative showed mixed success in postpartum care. The VBP initiative aims to align financial incentives with MCO performance on measures of care, access, and efficiency. In 2017, each MCO was evaluated on the percentage of deliveries that had a postpartum visit on or between 21 and 56 days after delivery. Of the 8 MCOs with performance assessed, two received incentive payments (≥78% of deliveries with timely postpartum visit), 2 were neutral (74-77% of deliveries with timely postpartum visits), and 4 had financial disincentives due to ≤73% of deliveries having timely postpartum visits.

For women with incomes above the eligibility limit for Medicaid but below 264% of the federal poverty level, the Family Planning Program provides a limited benefit covering contraceptive counseling and provision. Pregnant women with incomes between 138% and 264% of the federal poverty level are eligible for Medicaid, which then provides prenatal care, as well as postpartum care up to 60 days post-delivery. After 60 days, they are no longer eligible for Medicaid services, but can continue to receive family planning services. Of the 15,447 participants in the Family Planning Program in 2016, only 2,925 (19%) used one or more service. They also may be able to access subsidized private coverage through Maryland Health Connection.

Given the scope of services and high rate of coverage of low-income women and infants, HealthChoice MCOs have been identified as key stakeholders in addressing infant mortality.

CONCLUSION

Summary of coverage

Overall, we identified 83 programs that focused on infant mortality or its risk factors in the state of Maryland, which were equally distributed between state, local, and non-profit or other types of organizations. Of the identified programs, we were able to reach out to 43 programs that provided direct services to Maryland residents, of which 25 responded. While other programs in the state may address risk factors for infant mortality, this review focused on programs that provided preconception, prenatal, or postpartum care or services. From both data sources, the majority of services were concentrated around referral/care coordination, health education, safe sleep, pregnancy support/navigation, home visiting, and health education. These services can overcome barriers related to 1) awareness around health issues or concerns, such as pre-eclampsia symptoms or home safety, 2) transportation, by providing in-home visits, and 3) linkage and access to care, through coordinated referrals. Peer support/counseling and women's reproductive health services were also prominent.

Additionally, and ideally, these services could be offered throughout the preconception, prenatal, and the postpartum/intrapartum period. Nurses were the main providers of services in the programs surveyed, followed by health educators and social workers.

The programs mostly were targeted toward low-income populations. About half of all programs were in rural counties, but the highest number of programs were found in more populated counties. Of the programs surveyed, we found that the majority described their population as low-income, pregnant women. Additionally, women with substance abuse concerns and mental health conditions were also common, yet these services were less likely to be provided by their specific program (as described below). The surveyed programs also had a fairly even distribution of clients that were non-Hispanic black or African American, Hispanic/Latino, and non-Hispanic white, with non-Hispanic black clients as the majority. About half of the surveyed programs reported their clients reside in urban areas and about a third in rural areas.

Use of innovative approaches to reach clients

Another key component of the study was approaches used to meet additional needs of the clients. In particular, innovative strategies included information sessions in a variety of locations, including churches and beauty salons, utilizing community health workers in high-risk communities, telehealth or hotlines for counseling or questions/concerns, and having a male involvement coordinator for the teen health programs. These strategies offer opportunities to bring services to the client and their community, particularly in settings that are familiar to potential clients. This has been shown to better engage and build trust within the communities and, in turn, maximizes reach to a larger number of clients and usability of services among clients.⁶ Additionally, it was clear that some programs also service the broader needs of the clients by providing resources that address barriers to improving health or providing infant care, such as child care, GED preparation, or language services. In the case of outreach to providers, making training services accessible online and providing continuing education credit can also increase overall engagement in the program. Referrals were noted as a common way to reach clients; however, additional work group discussions suggested that this may be difficult to identify or refer clients when programs are not available within the community to address the specific reason for referral.

⁶ Black RE, Taylor CE, Arole S, Bang A, Bhutta ZA, Chowdhury AMR, Kirkwood BR, Kureshy N, Lanata CF, Phillips JF, Taylor M, Victora CG, Zhu Z, Perry HB. Comprehensive review of the evidence regarding the effectiveness of community-based primary health care in improving maternal, neonatal and child health: 8. summary and recommendations of the Expert Panel. J Glob Health. 2017 Jun;7(1):010908.

Programs also noted the use of incentives in helping to retain participation in the programs once clients have been reached. Specific suggestions for enhancing programs mentioned by program respondents were giveaways, as well as healthy and nutritious meals or snacks for program participants, and funds to support longer follow up with mothers and children.

Funding and Sustainability

Most programs reported concerns regarding financial sustainability, with challenges described for both grant funding and reimbursement. Competition for funding, changing priorities, and flat funding despite increasing costs were common concerns. Additionally, funding and resources to support special populations and services, transportation, and participant recruitment, enrollment, and retention were needed.

Many programs reported efforts to reduce costs, including strategic partnerships, sharing resources, dependence on volunteers, and other staffing modifications were ways to leverage resources and address unmet needs of clients, especially those that the program was not equipped to address. Respondents also highlighted the need for advisory board meetings, staff team building, and workforce development.

Identification of gaps

Gaps in services were also noted in this study. While many programs provided educational services, services that offer resources to enable clients to access care or address barriers to care were limited (e.g., language translation, cribs, adequate housing, child care). Many of the programs surveyed indicated broader social needs of their clients that their program could not specifically address, such as housing, transportation, child care, nutritional services, navigation support, and translation/interpretation. In particular, safe sleep resources were mentioned as a need, even though safe sleep services were commonly reported. This may be related to the need for resources that provide safe sleep rather than only education. Only a few programs mentioned providing cribs to families, which has been shown to be an evidence-based intervention. Mental health services and substance abuse were mentioned as a common issue of their client population; however, services for mental health and substance abuse were less commonly provided. The time periods during and surrounding pregnancy (preconception and postpartum) are unique with specific needs that should be addressed within

17

⁷ Moon RY, Hauck FR, Colson ER. Safe Infant Sleep Interventions: What is the Evidence for Successful Behavior Change? Curr Pediatr Rev. 2016;12(1):67-75.

programs. Available mental health or substance abuse programs could further incorporate this special population into their existing services. Additionally, resources to support breastfeeding, such as lactation consultants or breast pumps, or other nutrition services, apart from the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC), were less frequently mentioned in the web review and expressed as a need in the survey. Medical needs were also mentioned by program respondents, including low-cost medical assistance for those not eligible for Medicaid, dental services, and accessible prenatal care.

Finally, specific programs focused on teen pregnancy prevention were limited; however, we found that teens were mentioned more often as a special population within existing programs, such as family planning programs or programs for teen parents. Of the teen programs mentioned by the state, we could not identify which counties or communities were offering specific programs related to sexual education, rather the website indicated that funding is provided to local health departments or community partners who apply. Thus, it was unclear, which areas offered comprehensive sexual education through Maryland's Personal Responsibility Education Program (PREP), sexual risk avoidance based on promotion of abstinence through the Sexual Risk Avoidance Education Program (SRAE), or both. Given that abstinence-only education has been shown to be less (not) effective, there may be gaps in comprehensive services for teen pregnancy prevention if some counties only offer SRAE. This conclusion was based mainly on the website extraction; teen programs were not mentioned as a specific need in the survey responses. Overall, there is the potential to more explicitly incorporate these services in to existing programs within the state, such as during home visiting or through expanding pregnancy support and navigation services.

Study challenges and limitations

Overall, given the methodology applied, it is possible that programs are providing services related to infant mortality, its causes, or its risk factors, but were not captured in publicly-available documents (websites, online documents) or provided in responses on the survey. For the review of publicly available documents, our findings are limited to mention of specific services on the website or within program documents. While mention of services suggests that there is an explicit focus on this

⁸https://phpa.health.maryland.gov/mch/Pages/teenpreg.aspx

⁹ Santelli JS, Kantor LM, Grilo SA, Speizer IS, Lindberg LD, Heitel J, Schalet AT, Lyon ME, Mason-Jones AJ, McGovern T, Heck CJ, Rogers J, Ott MA. Abstinence-Only-Until-Marriage: An Updated Review of U.S. Policies and Programs and Their Impact. J Adolesc Health. 2017 Sep;61(3):273-280.

area within the program; however, it does not preclude programs from offering other types of services that may not have been cited in publicly-available documents. Similarly, some information was largely unavailable on websites, including program effectiveness, best practices, and challenges. The survey responses addressed this gap. Additionally, several students were involved in data extraction of publicly-available documents and, thus, we cannot rule out variation in extraction details or quality. This is inherent in the design and methodology applied. Finally, it was difficult to determine the frequency in which the services mentioned are provided and the extent to which these services are distributed differentially within the state (i.e., are some services concentrated only in specific areas and mainly urban or more populated counties?).

For the survey, we had an overall response rate of 58%, which is reasonable for this type of study and time constraints. When we stratified by methodology, we found that there was a much lower response rate among local health departments, which may reflect how the survey was distributed and other constraints. We had a much higher response rate (81%) for non-profit and community-based programs. Initial challenges with the survey included identifying contact information to distribute the survey and limited initial response rate for those contact. As a result, we applied additional strategies to increase awareness of the survey and its importance and to inform participants that their responses are needed to inform specific legislation for the state (2018 Md. Laws, Chap.83).

Feedback from MHCC and the workgroup was helpful in identifying additional programs for inclusion. Through this iterative process we aimed to increase the study's capture. This process also identified Medicaid Managed Care Organizations (MCOs) as providing crucial services focused on preconception, prenatal, and postpartum care, as well as infant health care services to large numbers of women in Maryland. While these programs are not included in this inventory report due to the specific parameters for this study, we reviewed Maryland MCO services as well as activities of stakeholders for the main report. These findings were also essential in the development of recommendations.

Despite these limitations, this study provides an overview of both public and private programs in Maryland that address infant mortality, its causes, and its risk factors. By identifying best practices, challenges, and additional services needed, these findings can support efforts to strengthen systems within Maryland to reduce infant mortality.

WEB EXTRACTION RESULTS

Table 1. Programs to address infant mortality or its risk factors in Maryland identified by web search criteria, by type of organization

Organization type	Number	%
Government agency - state	26	32.1
Government agency - county	31	38.3
Non-profit/Other	24	29.6
Total	81 programs	100
Total (excluding data collection or review/recommendation programs)	71 programs	87.7

Table 2. The percentage of infant mortality programs in Maryland that mention offering specific types of services based on review of websites and program documents

Type of service offered	Number	%
Referral services (behavioral health, substance abuse, pregnancy care, care coordination, case management, service linkage, etc.)	37	45.7%
Health Education (e.g., parenting classes, sex education, baby care kit, prenatal classes)	36	44.4%
Home visiting	34	42.0%
Peer (and family) support, counseling	16	19.8%
Family planning, women's/reproductive health care (e.g., STD screening/treatment)	15	18.5%
Pregnancy support and navigation (including doula services, pregnancy kits, birth plan)	13	16.0%
General prenatal care only	10	12.3%

Data collection, evidence review (PRAMS, FIMR, MMRC, Birth Defects, MD Patient Safety, Perinatal System Standards; Title V Block Grant reporting, MIEMSS Perinatal, Child Fatality Review, Breastfeeding Policy Recommendations)	10	12.3%
Substance Abuse (screening and/or counseling) (or Plan of Safe Care for Infants)	8	9.9%
Breastfeeding support (not education)	7	8.6%
Nutrition support (not education) (e.g., meal prep, planning)	6	7.4%
Teen Pregnancy Prevention (or Teen Parent support)	6	7.4%
Safe Sleep	4	4.9%
Smoking Cessation (screening and/or services)	4	4.9%
Mental health services	4	4.9%
Housing (e.g., transitional housing, home safety classes)	3	3.7%
Group prenatal care (if group care, often also provide individual)	3	3.7%
Other*	29	35.8%

^{*} transportation services, assistance in obtaining insurance or WIC, mother-infant care, primary care, father child program, language or deaf/blind services, policy/advocacy, child development screening, car seat safety, on-site childcare, Safe Haven, GED and adult education, errand support, resources to encourage reading to child

Table 3. Risk factors for infant mortality by the extent to which these services are provided in Maryland based on review of websites and program documents

Risk factors	Density of services to address risk factor
Risk factor - Clinical	
- Short birth spacing, young age at birth (family planning, teen pregnancy)	Moderate (FP, teen pregnancy prevention)
- Sexually transmitted infections	Moderate (women's health services)
- Other health factors (diabetes, hypertension, nutrition)	Low – nutrition (mainly through WIC) Moderate/High – prenatal care, primary care, pregnancy support
- Psychosocial risks (e.g., depression, anxiety)	Low – mental health services, but opportunities may exist within existing programs (e.g., home visiting)
Risk factor - Behavioral	
- Substance use/abuse	Low – substance abuse (not including referral services)
- Smoking	Low, but opportunities may exist within existing programs
- Access to care (primary, reproductive, prenatal, postpartum)	High (home visiting, prenatal care, reproductive, primary)
- Insurance	Low/Moderate (portion within programs)
- Social support (e.g., partner, family, IPV)	Moderate/High (peer support, pregnancy navigation, group PNC, limited mention of IPV but could be due to our inclusion criteria)
- Education (e.g., safe sleep environment, infant care)	High!
- Resources, income (to provide care, safe environment, breastfeeding, etc.)	Low (crib provision minimal, breastfeeding support/equipment, housing environment safety provisions)
- Neighborhood factors (e.g., housing, unsafe environment, transportation)	Low (Few safe sleep programs, safe housing/neighborhood not addressed, transport services mentioned in a few programs)
- Racism	Low (could be integrated within existing programs through CHWs, doulas, pregnancy navigators, language interpreters)

Table 4. The percentage of infant mortality programs in Maryland that mention offering services for a given demographic population based on review of websites and program documents

Demographic population	Number	%
Rural communities*	36	50.7
Pregnant women	30	42.2
Low-income, un- or underinsured	29	40.8
Non-pregnant mothers/women	21	29.6
Teens	17	23.9
Infants/Children	14	19.7
Racial/ethnic minority (incl. African-American, black women)	9	12.7
Fathers or family (mostly family, not specifically father)	8	11.6
Other**	10	14.1

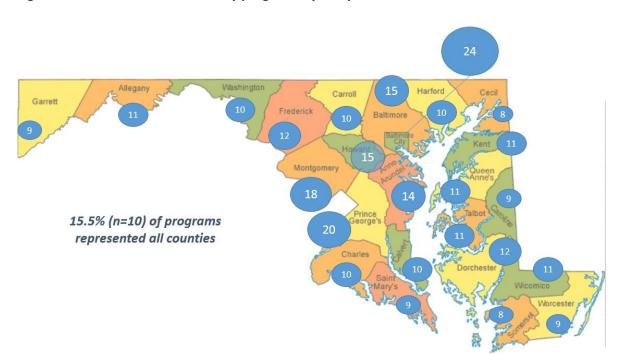


Figure 1. Number of infant mortality programs by Maryland counties

Table 5. Number of infant mortality programs, live births, infant deaths, and infant mortality rate by Maryland county

	BaltCo	Montg.	Anne Ar.	Prince G.	Harford	Freder.	Charles	Cecil	Saint M.	Wash.	Carroll	Howard	Balt.City	Wicomi co	Calvert	Allegh.	Worc.	Caroline	Queen A.	Somers.	Garrett	Talbot y	Dorch.	Kent
Number of programs	15	18	14	20	10	12	10	8	9	10	10	15	24	11	10	11	9	9	11	8	9	11	12	11
Live Births, 2017 (Vital Statistics)	9,829	12,634	6,895	12422	2623	2,714	1,837	1,143	1,351	1640	1,572	3,533	7,936	1,290	900	636	397	377	514	243	264	354	331	154
Average IM Rate, 2013- 2017	6.6	5	4.1	7.9	4	4.3	6.8	5.3	6.9	7.5	3.8	5.4	10.6	9.4	5.1	7	11.3	8.9	3.8	18.1	6.5	9.5	10.4	10
Number of Infant Deaths, 2013- 2017	313	325	180	483	54	60	73	31	49	64	26	95	400	58	24	25	24	17	9	23	14	16	10	8
Live Births (2017) per Program (Ratio)	655	702	493	621	262	226	184	143	150	164	157	236	331	117	90	58	44	42	47	30	29	32	28	14
Infant Deaths (2013-2017) per Program (Ratio)	44	39	35	31	26	19	18	18	17	16	16	16	14	11	9	5	5	5	4	4	3	3	2	1

SURVEY RESULTS:

Program Characteristics

Table 6. Organization type (n=25)

Type of program (% of programs)	Percent
County or state health department	40.0
Private non-profit	36.0
Community-based organization	12.0
University	4.0
Other (FQHC)	4.0

Table 7. Types of services reported by programs (n = 25)

Types of service (% reporting each service)	Percent
Referral services	88.0
Safe sleep	88.0
Pregnancy Support/Navigation	76.0
Reproductive health/family planning*	69.6
Smoking Cessation	64.0
Home visiting	60.0
Peer support	60.0
Health Literacy	56.0
Nutrition	56.0
Fetal Infant Mortality Review	48.0
Mental Health*	47.8
Substance Abuse	44.0
Teen Pregnancy Prevention	40.0
General Prenatal Care	32.0
Group Prenatal Care	32.0
Housing	12.0

Other (baby showers, car seat installation and education, substance use disorders,	
diaper bank services, labor doula support, parenting classes, prenatal education, STD	44.0
screening, vaccination, outreach to Behavioral Health facilities)	

^{*} Out of 23 programs. Response options added after 2 programs had already responded

Table 8. Types of providers used by programs (n = 25)

Provider types (% reporting each type of provider)	Percent
Nurses	72.0
Health Educators	52.0
Social workers	44.0
Community Health Workers/Pregnancy Navigators	40.0
Physicians	36.0
Nurse practitioners	36.0
Mental health providers (including substance abuse counselors)	36.0
Health Administrators	32.0
Nurse midwives	20.0
Physician Assistants	12.0
Other (CNAs, Insurance Navigators, Patient-Client Drivers, Care Coordinators & Assesssors, Certified Professional Midwives, Community Care Coordinators, Community Care Associates, Ombudsman, Doulas, Family Resource Specialists, Family Education Specialists, Medical Assistants, Registered Dietician, Peer Support Persons, Certified Passenger Safety Technicians)	36.0

Table 9. Types of outreach efforts reported (n = 25)

Outreach efforts (% reporting each type of outreach effort)	Percent
Self-referral, word of mouth	80.0
Referral from a medical professional	76.0
Referral from social service professional	72.0
Referral from early intervention service professional	64.0
Referral from education professional	60.0
Direct marketing/advertising	56.0
Referral from other entity	40.0
Other (DSS, Community Resource programs, Healthy families, LHD programs, Maryland Department of Health, WIC program, court mandate, health department referral, social worker at hospital, MCHP)	40.0

Client Demographics

Table 10. Population characteristics reported (n = 22)

Population characteristics (% of programs reporting each subgroup)	Percent
Low-income families	90.9
Pregnant women	90.9
Postpartum women	77.3
Women with substance abuse concerns	63.6
Women with specific mental health conditions (Specified as: anxiety, depression, bipolar, previous birth PTSD, perinatal mood disorder, postpartum depression, any)	59.1
Urban area	54.6
Women with specific medical conditions (Specified as: lack of prenatal care, nutritional support, age-related conditions, preeclampsia, trauma/violence related medical issues, diabetes, hypertension, cholestasis of pregnancy)	45.5
Specific race or ethnicity (Specified as: African Americans, Latinos, People of Color, Immigrants, Refugees, Afghan refugees, All races and ethnicities)	45.5
Rural area	40.9
Suburban area	36.4
Other (Undocumented, displaced, immigrant, migrant, women with child bearing capability)	9.1

Table 11. Parent and infant subgroups served by programs (n=25)

Parent and infant subgroups served (% of total clients served by all programs)	Percent
Non-pregnant mothers (including postpartum)	35.1
Pregnant women	26.2
Infants	11.0
Fathers	7.8
Other (General population, home births, teenage pregnancy, children 5-18, women of reproductive age)	20.0

Table 12. Race/ethnicity distribution of clients within programs (n=22)

Race/ethnic distribution (mean, % served by program)	Mean
Non-Hispanic Black or African American	35.5
Hispanic/Latino	30.2
Non-Hispanic White	27.1
Non-Hispanic Asian	0.9
Non-Hispanic other race	0.8
Non-Hispanic American Indian/Alaska Native	0.2
Non-Hispanic Native Hawaiian or other Pacific Islander	0.0
Other	0.8

Table 13. Age distribution of clients within programs (n=22)

Age distribution (mean, % served by program)	Mean
< 20 years	8.8
20-24 years	23.4
25-29 years	23.0
30-34 years	13.9
35-39 years	8.3
40+ years	4.5

Table 14. Education distribution of clients within programs (n=22)

Education distribution (mean, % served by program)	Mean	
Less than high school degree	31.9	
High school degree	46.6	
Some college/Technical or trade school	10.6	
Bachelor's degree	8.7	
Master's degree or higher	2.2	

Table 15. Rural/urban distribution of clients within programs (n=22)

	Rural/urban distribution (mean, % served by program)	Mean
Urban		47.2
Rural		34.8
Suburban		13.5

Table 16. Counties where clients reside (n=22)

Counties where clients reside (% reporting each county)	Count	Percent
Baltimore City	9	40.9
Prince George's County	9	40.9
Anne Arundel County	5	22.7
Frederick County	5	22.7
Baltimore County	4	18.2
Harford County	3	13.6
DC Metro Area*	2	9.5
Charles County	2	9.1
Dorchester County	2	9.1
Howard County	2	9.1
Montgomery County	2	9.1
Talbot County	2	9.1
Allegany County	1	4.6
Calvert County	1	4.6
Caroline County	1	4.6
Carroll County	1	4.6
Queen Anne's County	1	4.6
Saint Mary's County	1	4.6
Washington County	1	4.6
Cecil County	0	0
Garrett County	0	0
Kent County	0	0
Somerset County	0	0
Wicomico County	0	0
Worcester County	0	0